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ABSTRACT

This manual describes the "New Hampshire Leadership Series," a leadership training program designed to assist individuals with disabilities and their families to create a vision for themselves and to achieve positive futures. The manual is divided into six major sections. The first section, "Introducing the New Hampshire Leadership Series," provides the history of the leadership training series and discusses the effectiveness of the program. The second section, "Step-by-Step: Creating the New Hampshire Leadership Series," describes the necessary ingredients to running a successful leadership series. An overview of the series is presented, including the staff who run the series, how participants are selected, and how leaders in the field are secured to present during the six two-day sessions. The third section, "Session Content," discusses the format and dynamics of the sessions. Topics of the sessions include: parents' dreams for their children, practices and ideas for making dreams a reality, the legislative process and how to change laws, and community organizing strategies, and negotiation skills. Following sections of the manual include: "Funding the Leadership Series," "The Evaluation of the Leadership Series," and "Leaders Tell Their Stories." Appendices include nomination process forms and letters, application forms, session agendas, and budget and fund raising letters. (CR)

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FROM VISION TO REALITY

A Manual to Replicate the New Hampshire Leadership Series: Working with People with Disabilities and their Families to Create Positive Futures

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"Leadership gave me a vision of a positive future for my child; it gave me the self confidence to dream and design my own vision; and, the self confidence and skills to make my dreams a reality!"

1988 New Hampshire
Leadership Graduate

Acknowledgments

There are so many people to thank for creating and sustaining the New Hampshire Leadership Series, as well as for helping to write this manual.

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And of course we thank all of the graduates of New Hampshire's Leadership Series. They are the ones who create both the vision and the reality.

"Leadership has taken the mystery out of the process and shown me that I can affect change."

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"In order to make a change and a difference, you have to put your expectations very high and work toward them. Leadership taught us that nothing is impossible!"

Forward

by Beth Dixon

I was invited to participate in the Institute on Disability/UAP's first Leadership Series in 1988. At that time, I had never heard of the Institute and couldn't imagine why I had been nominated to participate. My qualifications, I assumed, were my four children—including my five-year-old son who had disabilities. At that time, life was hectic. I was very busy trying to be everywhere I needed to be—doctors' offices, therapy visits, four different schools in Concord, my own business, and yes, even occasionally home. After being convinced by my husband that the world could go on without me for a few days, I made a commitment to attend the three two-day sessions at the University of New Hampshire. Those six days dramatically changed my life.

As I entered the conference room on that first day of the Leadership Series I was very nervous and not at all sure what I was doing there. The session began with introductions and I felt that many of the participants were a lot more knowledgeable about the issues than I was. I remember introducing myself as "just a parent," but before long I learned there is no such thing as "just" anything.

I quickly discovered that the parents in this room shared many of my fears. We had faced similar struggles, and we shared a common desire to make the lives of our children the best that they could be. Unfortunately, we had no idea what the "best" was or how to make it happen. We hadn't yet learned that it was okay to create visions for our children that were more "typical" than "special." At the same time, most of us felt that what our children were getting was not good enough. We felt as if we were just settling for what professionals told us was possible. We hadn't yet dared to dream.

That was the beginning of the very first New Hampshire Leadership Series. The goal of that Series, as for all subsequent Series, is to empower families and individuals with disabilities with knowledge and skills, and to create camaraderie. There were 33 parents selected to attend that first Series—each one nominated by representatives from their regions for their leadership abilities. Throughout the Series we heard from professionals, adults with disabilities, and other parents who had achieved positive outcomes for their sons and daughters. For six days we received the latest and best information in the areas of education, positive behavioral approaches, family support, employment, housing, community organizing, and the legislative process. My head began to swirl with all of this new information.

The presenters were inspirational, but what was most valuable to me—and to most of us—was what we learned from each other. We listened

"Parents and people with disabilities have all the power. Unless they make their wishes known, the system will not change."

to each others' stories and cried each others' tears. A bond formed that is impossible to describe. To this day, we all know that when support is needed—in a small way, such as brainstorming ideas on the phone, or on a larger scale, such as in organizing a letter-writing campaign, attending a legislative hearing, or testifying at a school board meeting—we can count on each other to be there.

The Leadership Series helped me rediscover the ability to dream and provided me with the strategies to make those dreams come true. My dream—to have my son's life be both "regular" and extraordinary—has come true. Andrew now attends a regular fifth grade class, goes to the local Boys and Girls Club after school and summers, has friends, goes to parties, and loves life. This is in direct contrast to the future that had been predicted for him. For too long I had heard about all of the things that Andrew *couldn't, wouldn't, and shouldn't* ever do. Leadership helped me to focus on all of the things he *would, could,* and (probably) *wanted* to do. It taught me to look for the positives instead of the negatives, for his strengths and not his weaknesses. It taught me the meaning of the word "typical" and to believe in the phrase "*only as special as necessary.*" It helped me change my son's life.

The Leadership Series also changed my life. I now work with the Institute on Disability/UAP and have coordinated the Leadership Series since 1990. Each year I am impressed with the new group of Leadership participants' determination and creativity to make the world a better place for their children and for themselves. I have learned that change doesn't ever happen quickly or without struggle, but it is well worth the energy and time it takes. I have also learned that bringing people together makes any struggle much easier. Most importantly, I have learned that having a vision is the first step to changing the world.

Introduction

Over the past decade, leadership training series have gained increasing popularity in many states as an innovative and successful approach to creating positive futures for people with disabilities and their families. This approach assumes that family members and individuals with disabilities, when given vital information about exemplary practices and disability issues, can gain the power necessary to create important sustainable change. Through leadership training, family members and individuals with disabilities are recognized as key change agents and provided with support to assume leadership roles. This support includes information delivered from leaders in the field of disability and community inclusion, and also whatever child care, respite, personal care attendants, overnight accommodations, meals, and travel expenses are necessary to complete the training event.

Modeled after, Minnesota's *Partners in Policymaking*, the *New Hampshire Leadership Series* was developed in 1988 to assist individuals with disabilities and family members to create a vision for themselves and to achieve positive futures. The Series continues to undergo revisions and expansions in order to reflect the ever-changing issues faced by individuals with disabilities and their families. Despite ongoing change, certain themes remain constant, such as: the importance of belonging in fully inclusive communities; family support through the provision of resources; supporting family choices; community-based child care and early education; full time participation in neighborhood schools and typical classes; naturally supported employment; and, home ownership.

The audience for this manual is varied. Individuals with disabilities, family members, state and national leaders, and professionals in the disability field will find this manual helpful in designing strategies to promote the full inclusion of people with disabilities in all aspects of community. The information will assist the reader in achieving a solid understanding of the importance of leadership training for individuals with disabilities and their family members, as well as provide a step-by-step approach to creating a leadership training series.

This manual is divided into six major sections: *Introducing the New Hampshire Leadership Series; Step-by-Step: Creating the New Hampshire Leadership Series; Session Content; Funding the Leadership Series; The Evolution of the Leadership Series; and, Leaders Tell Their Stories.* These

"To me, the most important thought I am leaving Leadership with is that I'm allowed to dream of a great life for my son. So many times I've been told to be realistic, be practical, get real. I almost cheated Jimmy out of the kind of life he deserves. My child is not broken. He doesn't need to be fixed."

sections will provide the reader with a comprehensive understanding of the New Hampshire Leadership Series as well as the steps necessary for replication. This manual is the result of eight years of information and strategies gathered through the experience of leadership development for people with disabilities and their families in New Hampshire. Leadership graduates are responsible for all quotes and stories included in this manual.

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Introducing the New Hampshire Leadership Series

History of the Leadership Series in New Hampshire

New Hampshire has achieved national recognition in recent years for its innovative approaches to supporting people with disabilities and their families within their communities, and for fostering communities where everyone belongs. In New Hampshire, attending regular classes in neighborhood schools, home ownership, employment, family support, and access to quality health care and assistive technology are common experiences for individuals with disabilities and their family members. New Hampshire was not always a state that could boast of such opportunities. Substantial positive changes have taken place during the past few years. Many of these changes are a direct result of the work of leaders who have graduated from the New Hampshire Leadership Series.

In 1988, the University of New Hampshire, Institute on Disability/UAP received a grant from the Developmental Disabilities Council to organize New Hampshire's first Leadership Training Series for parents of children with disabilities. This series provided 33 parents with state of the art information and strategies to effectively impact local and state organizations on issues related to people with disabilities. The outcomes from this first Leadership Series were so successful that the event became the model for annual leadership training in New Hampshire. The Series was modeled after Minnesota's *Partners in Policymaking Series* with later input from the *Colorado Partners in Leadership Training*.

Since 1988, the Institute on Disability/UAP, in collaboration with the Developmental Disabilities Council, People First, the New Hampshire Division of Mental Health and Developmental Services, Department of Education, and other organizations, has sponsored a Leadership Series each year for individuals with disabilities and family members.

Each year the Leadership Series is updated and revised. Some modified versions of the Series have been conducted in order to address specific issues in the state. For example, two leadership training series were specifically oriented toward the needs of families of young children (from birth to six years of age), and another Series focused on issues related to assistive technology. In 1994 the Series was expanded from its original three, two-day sessions to the current longer format of six, two-day sessions. This change occurred to accommodate the increasing amount of information requested by participants.

Over 200 parents and adults with disabilities have graduated from the New Hampshire Leadership Series. These leaders have a clear vision for themselves and their family members with disabilities and a knowledge of state-of-the-art supports for individuals with disabilities. They are

"It is extremely difficult to get away at anytime due to the unique needs of my family. Participation in this Series would not have been possible without the support I received."

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skilled in advocating with service providers, using the legislative process to achieve change, and organizing communities to support inclusion. Families and individuals with disabilities are using their combined strength and determination to change laws, persuade schools and businesses to include individuals with disabilities, and educate all aspects of community on the importance of welcoming and including every member. They serve on school boards, family support teams and councils, judicial benches, local and state government, community boards etc. When asked about their entrance into the world of leadership positions, many graduates point to the New Hampshire Leadership Series as a pivotal experience in their lives.

New Hampshire's Success Story

The effectiveness of the Leadership Series in New Hampshire and other states involved in similar efforts has offered striking confirmation of what many had known all along - that the best way to create positive change is to educate those individuals most directly affected by laws, policies, supports, and services for people with disabilities. By bringing together individuals who share the same struggles and providing information on exemplary practices and strategies to organize for change, family members and individuals with disabilities gain the necessary advocacy skills and confidence to influence policies and change systems. Who better to advocate for quality inclusive lives for people with disabilities than the people themselves? What voice has more credibility to policymakers and service providers than the voice of those who are impacted by the policies and individuals who use the services?

At many different levels, both public and private, throughout the state leadership graduates have affected change. Two bills were passed into law by the New Hampshire legislature in 1989: one to create a comprehensive system of family support and another to reduce the waiting list for adult services. To affect this change, graduates from the first Leadership Series organized telephone networks, invited legislators into their homes, and testified in large numbers at public hearings. Following passage of the family support legislation, 80% of the Leadership Series participants served on their local Family Support Councils. Several parent groups led by Leadership graduates have sprung up around the state and many participants have become involved in parent and support organizations at the local and state level. Undoubtedly, the New Hampshire Leadership Series has been a catalyst for change in tangible and profound ways.

The information presented in this manual is a compilation of "*the best of*" the New Hampshire Leadership Series. Relevant materials and procedures have been assembled to replicate what has been done in New Hampshire and to present the flavor and the feeling of the New Hampshire Leadership Series. The format of this manual will help readers understand the importance of leadership development, and by using and modifying the organizational materials and forms contained in the Appendices create their own Series.

"Leadership confirms that you are not alone, that you can make a difference. Knowing that is very freeing."

Step-by-Step: Creating the NH Leadership Series

This section describes the necessary ingredients to running a successful Leadership Series. An overview of the Series is presented, including the staff who run the Series, how participants are selected, and securing leaders in the field to present during the six two-day sessions.

Overview of the Leadership Series

The concept behind the Leadership Series is fairly straightforward. For six two-day sessions (a total of twelve days), parents and individuals with disabilities leave behind the responsibilities of their daily routines and focus solely on the issues that so strongly impact their lives. To help establish the right context and free participants from the worries of everyday life, all participants are provided with good food, fine accommodations, and all necessary travel and child care expenses. Hotel facilities are selected for the Series based upon their accessibility for individuals with disabilities, ability to accommodate the large group, quality of their food, and courtesy of service. Because a portion of the Series involves meeting with state legislators, it is helpful to select a location that is within easy driving distance to the state capital.

Sessions are typically scheduled four to six weeks apart so that the entire Series takes about eight months to complete. Additional time is provided between sessions around the holiday season. During each two-day session, national, international, and state leaders as well as local policymakers share with participants the latest available information about achieving the vision of quality lives for individuals with disabilities and their families. Participants receive binders organized by sessions and topics. Reading material is distributed during each session to assist in the education process. At the end of the first session, everyone receives a T-shirt with the leadership logo and an inspirational quote. Photo collages of individuals, families, and significant events are displayed throughout the Series. Fieldwork assignments are assigned between each session to focus participants on specific tasks forming and realizing their vision within their local communities. During each session, time is scheduled for participant updates. Sharing in one another's struggles and successes creates an interest, commitment, and a strong bond among participants.

"The most valuable aspect of Leadership for me was the chance to meet, talk, and share experiences with others at the conference... from parents...to people with disabilities...to presenters."

Staffing the Leadership Series

The New Hampshire Leadership Series is supported by three part-time staff. These staff members handle all correspondence and communication related to the Leadership Series as well as attend the Series to provide

continuity throughout the sessions. Staff members include two former Leadership graduates and support personnel involved in leadership development since 1988. Leadership Series staff facilitate a network of people and organizations to share state of the art practices and strategies to create change.

Fund raising, revising agendas, developing field work assignments, and communicating with participants and presenters are activities that continue throughout the life of the Leadership Series. Despite the fairly intensive effort required to conduct the Leadership Series, the excitement and anticipation of meeting a new group of future leaders never wanes.

Selection of Participants

Leadership Series participants are selected through a rigorous process of nomination, application, and selection. The application process begins with a nomination in writing. Nominations come from self advocacy organizations, developmental service agencies (called area agencies in New Hampshire), parent groups, family members, independent living centers, friends, acquaintances, teachers, principals, or other people such as neighbors. The nomination form is contained in Appendix A.

Nominees receive a letter of introduction and an application form (Appendix B). The form asks about the applicant's family, experiences, community involvement, and special interests. Taking time out of a hectic schedule to complete and return the application form is often a difficult first step for the applicant. Individuals who need assistance in completing the application are provided with whatever support is necessary (by telephone or personal interview) to apply.

In order to promote cohesion among the group, space is limited to 30-40 participants. Usually more applications are received than can be accepted. A committee of approximately seven people meets to review the applications and make the difficult decisions of acceptance or denial. The committee consists of past Leadership Series graduates, policymakers, representatives from parent organizations, the Independent Living Center, and People First of New Hampshire. Decisions are based on the applicants' commitment to attend all of the sessions, demonstrated leadership experience, diversity of background, geographical distribution, age of family member with a disability, and disabilities represented. The Leadership Series works best when participants represent a diverse group of people from each region of the state. The application process is designed to reinforce the notion that participants represent a select group of individuals with leadership potential and an important mission.

Letters are sent out (Appendix C) to notify applicants of the committee's decision. Individuals who are not selected are placed on the Institute on Disability/UAP mailing list to receive information about upcoming training and are encouraged to apply again the following year.

Applicants who are selected return a signed confirmation form and contract, and receive information about the financial reimbursement process (Appendix D). Participants are expected to make arrangements for travel, vacation time, child care, personal care attendants, and overnight lodging at the conference site. All of these expenses are reimbursed by the Leadership Series. Participants who reside in the same geographical region are given each other's names and addresses to assist them if they wish to travel together.

Education by Current Leaders

While the selected individuals are preparing for their participation, Series organizers are busy securing state, national, and international leaders in the field of disability and community inclusion as presenters for the Series. The presenters represent a blend of leaders in the fields of self advocacy, education, employment, community living, assistive technology, family support, negotiation skills, the legislative process, and community organizing. Presenters use a variety of interactive strategies such as role playing, cooperative learning, and small group discussion to involve participants in the learning process.

Presenters and session facilitators come from a variety of backgrounds with a common thread woven among them. This common thread is the belief that all people regardless of their differences belong in all aspects of local communities. Expectations of presenters include: the delivery state-of-the-art information through a variety of interactive formats; the use of people first language; and the ability to set an example of high expectations and successful achievement of dreams for individuals with disabilities and their families. Often, presenters are selected based on recommendations from other people involved in leadership development for individuals with disabilities and their families.

Each of the six sessions begins with a formal welcome by a state policymaker, who articulates support for the leadership process. As illustrated by the sample agendas (Appendix E), the curriculum of the Leadership Series is ambitious and broad. There are few topics of concern to individuals with disabilities and their families that are not included in the scope of the Series. The following section describes the content of a typical Series.

"The most valuable aspect of Leadership for me was meeting people who were distinguished by their decency. Also, meeting people with disabilities—something that just isn't part of the rest of my life."

Session Content

Session One: The Leadership Series Begins

New Hampshire Leadership participants travel many roads to arrive for the first day of the Series. As they walk in the door, they are welcomed with warm smiles and a buffet lunch from the Series organizers. They are given a name tag, a three ring binder with initial resource materials, and blank paper for taking notes. After the state policy maker welcome address, Beth Dixon, a parent and coordinator of the Leadership Series, opens the day and asks the participants to introduce themselves. The introductions are short and concise, dealing with the most basic facts. Everyone wears a name tag and nervous smile. A sense of anticipation fills the room. Each participant brings different expectations, different backgrounds and experiences, and different needs to the Series. Yet all share an as yet unspoken desire to develop the most positive futures for themselves and their children.

Following the introductions, participants are asked to talk about their vision for themselves, their children, and their families and their recent experiences. Each of the six sessions begins with these participant "updates."

As the Series progresses through the six sessions, the atmosphere quickly changes from the nervousness of the first gathering to one of camaraderie. Greetings are exchanged. Everyone is on a first name basis. The room is alive with conversation. Getting the attention of the audience is not easy. Eventually, participants settle in and the first item on the agenda—family updates—begins. Unlike the brief introductions of the first day, a stopwatch is needed to keep personal updates to the three minute time limit. Some participants find that in just a short period of time, many changes have taken place in their lives. Some stories leave the audience laughing. Others bring tears. The room is charged with an electrifying energy as each story unfolds—a child's accomplishments, a stressful meeting to advocate a move from a segregated to an inclusive environment, connecting with other people in a community.

Following personal updates, each session includes a panel of Leadership Series graduates who share how leadership has made a difference in their own lives. For many participants this is the highlight of the Leadership Series. Participants lean forward in their chairs and question the speakers closely as each one relates his or her story. The following stories illustrate some of the triumphs and struggles participants hear from members of the panel.

Leigh, a mother of three young children, begins with stories about her son, Peter. Leigh attended Leadership shortly after Peter was born and developed a strong commitment never to allow Peter to be segregated from his peers or society. From the beginning, Peter participated in family

"The enthusiasm and energy of the presenters was infectious. The variety of approaches to communication and strategies to affect change were valuable tools. I leave Leadership with a big bag of tricks to improve the quality of life for me and my family."

and community events. He entered day care at age two and began in a regular preschool at age three. The message Leigh gives the participants is crystal clear—inclusion right from the start!

Kathy and Tom share amusing stories of their large blended family and discuss how their daughter, Heather, had been educated in a segregated setting. Kathy and Tom move the participants with the story of how they succeeded in getting Heather enrolled in her neighborhood school. They read the letter they wrote to the superintendent, principal, and school board members that described the reasons why Heather deserved to be a part of the same school system as her brothers and sisters. This powerful testimony and the support from family and educators allowed Heather to be welcomed as a full-time student in her local school.

Joseph never fails to inspire the participants of the Leadership Series. While other stories bring laughter, cheers, and hope, Joseph's story is one of segregation and disillusionment as he describes his son, Joe, who spent his school years in institutions and segregated classes ("18 years of kindergarten"). Joseph's story clearly illustrates the need to remember the history of people with disabilities, and helps listeners vow to never let the outdated ideas of the past return.

Developing the Dream

The remaining portion of the first session consists of workshops conducted by parents and self advocates. Nationally known speakers Tom Powell or Jeff Strully, both parents of children with disabilities, and Patrick Worth or Norman Kunc, self-advocates, lead participants through exercises to set the vision for their children and themselves. Discussion centers around people being involved with friends and family in ordinary places doing everyday things. What are your dreams for your child? What are your dreams for yourself? What are your dreams for the future?

Jeff Strully begins his presentation with the story of two teenagers. The first teenager is a young woman with many gifts and talents, whose life is filled with joy and friendship, and whose future is filled with hope and excitement. A very different story emerges as he speaks of the second teenager. He talks about the many labels and disabilities this woman has. He mentions all she cannot and will never do. He paints a picture of a young woman with a dreary future. When the story ends, an audible gasp escapes from the audience. Jeff, in fact, is describing the same person. There is only one young woman, his daughter Shawntell. Who she is depends upon how he—and others—see her. Jeff's message is clear. If participants view themselves or their children in light of their limitations,

the rest of the world will view them the same. Participants must see their gifts or their children's gifts and make certain others do too. Participants keep this story in mind throughout the Series as they describe themselves or their children as people with abilities and gifts to share.

Patrick Worth's personal story of segregation and abandonment teaches participants that belonging is important to each person and that the differences among us must be celebrated as integral components of a complete community. Patrick shares from his first hand experience that the most serious disability is loneliness and ostracism from a society which values perfection. Patrick explains the strategies he has found effective for gaining power and control over his life to achieve his dream of belonging.

"The American Dream" is a name we give to the ideal all of us want to achieve. Tom Powell reminds participants that this dream—a good job, a happy and healthy family, a nice place to live—is part of our American culture. Why is it denied to Tom's son, Nick, and to so many other Americans simply because they have a disability? To drive home his point, Tom tells the story of his son's "career" in a sheltered workshop and of the struggle to find Nick a decent job and place to live. With anecdotes and humor, he puts into words the thoughts and feelings many participants share: The idea that each person deserves the right to achieve the "American Dream." He gives participants strategies to achieve this dream for themselves and their families. One by one, participants come forward with their visions and together the group discusses how these visions can become a reality.

Combining his personal experience with professional expertise, Norman Kunc expresses his views on disability, belonging, and diversity in a powerful and dynamic way. He challenges participants to think about the powerful messages that are received by children and adults with disabilities. What message does segregation give to people about their worth in society? Does therapy and remedial education teach people to value their gifts and abilities? Isn't it natural that people who are taught to dislike their differences wind up disliking themselves? These difficult questions spark earnest discussion among participants. Norman's paraphrase of the old axiom, "actions speak louder than words," assists the participants in forming a commitment to take concrete action to reach the goals they have set.

At the end of each day, participants enjoy a casual dinner. The setting is informal and participants linger over coffee and exchange stories. Most participants stay overnight at the conference site—some staying away

"Hearing other people's experiences was a shot in the arm toward realizing what was important to me and what I should focus on."

from their children or family for the first time. Getting away from the everyday hassles and commitments of family life gives participants time to take a breath and mull over what they are hearing and how it relates to their own lives. Occasionally an evening session with the presenters is held and work continues far into the night. Fieldwork assignments are given out at the end of the second day of each session (Appendix F). For the first assignment, participants are asked to develop a vision for their child, their family, or themselves and to bring in photographs of their families. Each assignment following the first session builds on that vision and the steps necessary for achievement.

Sessions Two-Four

With the second and all succeeding sessions, formalities among participants disappear. The room is no longer a room of strangers, but a gathering of colleagues drawn together by a common sense of purpose. A photo display board is created from the family photos brought by the participants. The collage of smiling faces reflects a growing sense of camaraderie amongst participants. Throughout the weeks and months ahead, phone calls are exchanged, information is read and reread, letters are written, and changes are beginning.

The major focus of the second through fourth sessions of the Series is giving participants up-to-date information on practices and ideas that impact the lives of individuals with disabilities. Presenters from across the state and country address Series participants and provide the most current available information on best practices and the how-to's for making participants' dreams a reality. Topics include education, friendships, recreation, assistive technology and communication, positive behavior approaches, employment, housing, and family support. Some presenters are the staff of the Institute on Disability/UAP. The Institute is fortunate to have several staff members who are actively working on training, demonstration, and other projects in these areas. Other speakers are brought in based on their expertise in a particular area. The three-ring binders begin to fill with resource materials and handouts on each subject area.

Fieldwork assignments (Appendix F) continue to be a focus for participants between sessions. Participants use these assignments as an opportunity to work to achieve their vision and develop supportive connections throughout the state and in local communities.

Session Five

An important aspect of leadership is understanding how laws and policies are formulated and influenced. This process is a major focus of the fifth session titled, *Changing Laws to Create a Positive Future for All*. Allan Bergman of the United Cerebral Palsy Association brings his experience with the legislative process and communicating with policy makers to the New Hampshire Leadership Series. He explains how a bill is introduced and the path it travels to become a law. Participants receive information on testifying before a legislative committee, developing a telephone tree, establishing letter writing campaigns, and influencing legislators.

During day two of this session, New Hampshire state legislators are invited to a round table discussion sponsored by the Leadership Series at the New Hampshire State House. Small groups of four to five participants make presentations on topics of interest to them, such as inclusion in schools, health care reform, or fair housing. Legislators circulate among the groups giving feedback on presentation style and content. Participants learn by seeing issues from the legislator's point of view and receiving answers to their questions, such as "What do legislators need to hear from constituents?" "What are the next steps?" "How do constituents best educate their legislators?" More importantly, legislators receive information and opinions from their constituents on a variety of "hot" topics. What are the greatest areas of need for people with disabilities? What are the priorities? How can the stumbling blocks towards positive change be removed? What statewide supports can be provided to create positive futures for all New Hampshire citizens?

"I now have more confidence in my advocacy for my son. I learned that we have a voice. We can support each other and promote change."

Session Six

As the final topic of the Series, *With a Vision and Voice*, several national speakers present on community organizing strategies and negotiation skills. Greg Galluzzo from the Gamaliel Foundation of Illinois, and Rich Male and Dan Lopp from the Community Resource Center of Colorado, or members of the national organization ADAPT share their expertise. Through small group exercises and role playing, participants gain skills in conflict resolution, practice negotiation tactics, and handling adversity. The session ends on an exhilarating note with participants prepared to go back to their communities with new insights, a final fieldwork assignment, and a sense of what can be accomplished with a vision and a voice.

Participants depart from the Series exhausted, overwhelmed, and exhilarated. Strengthened by the stories and ideas they have heard and the

support they feel from the group, each participant leaves the Series with a shared commitment to live his or her dream. Addresses and phone numbers are exchanged and promises to stay in touch are made. A reunion is planned for all participants. Participants return to their family, friends, and community.

Funding the Leadership Series

Because the Institute on Disability/UAP is committed to furthering its efforts toward leadership development, funding the New Hampshire Leadership Series continues to be a challenge. In some states leadership training programs are funded solely by the state Developmental Disabilities Council. In New Hampshire, securing financial support beyond the contribution from the Developmental Disabilities Council is necessary. We have found requesting smaller amounts from a variety of resources to sponsor individuals or components of the Series to be a successful approach to raising funds. For example, an organization may agree to purchase the T-shirts or "sponsor" one participant from their local region. Where the financial commitment of sponsoring organizations is kept small, more people can become invested in the process. The investment of sponsoring individuals is returned in the form of new leaders in local communities who can assist organizations in a variety of ways. Information about the budget and fund raising strategies for the Leadership Series are contained in Appendix G.

"If we, as parents,
can't see capacity,
gifts, strengths, talents,
and abilities,
no one else will!"

The Evolution of the New Hampshire Leadership Series

The Leadership Series is constantly evolving to meet new challenges. The curriculum is continually updated to meet the changing needs of individuals with disabilities and their family members. As more information is added, the agenda has expanded and the number of sessions has increased. Recent additions to the list of topic areas include the history of self advocacy and the parent movement, skills to facilitate a meeting, issues of independent living, and the impact of assistive technology. Some of these additions reflect an increasing emphasis on adults with disabilities participating in the Series, whereas the earlier Series participants were primarily parents. People with disabilities as well as their family members now are strongly encouraged to submit applications for the Series. In addition, persons with disabilities are featured speakers during every session.

As each Series ends and a new group of leaders emerge, increasing attention has been focused on the need to maintain a broad, statewide connection to the 200+ Leadership Series graduates. Aside from informal reunions that participants organize annually, the Institute on Disability has begun offering an Advanced Leadership Series to graduates. Advanced Leadership Series events provide graduates an opportunity to reunite and use their leadership skills to focus on issue specific changes in New Hampshire. For example, 50 Leadership graduates are currently undergoing training and strategizing on the future of family support in a managed care environment. The advanced Leadership Series requires a three-day commitment over the course of six months. As usual, all travel, child care, meals, and material expenses are covered for participants. As Leadership participants graduate, and new issues emerge, individuals with disabilities and their families can count on the statewide structure of the New Hampshire Leadership Series to change their visions to reality!

"We need to dream about unlimited possibilities. If you can reach it and touch it quickly, it's not big enough!"

Leaders Tell Their Stories

It is the stories of those whose lives have dramatically changed as a result of their participation that provide the inspiration to continue and improve upon the Leadership Series. Such stories are the heart and soul of the Leadership Series and inspire and motivate new participants each year so that new stories of leadership continue to unfold.

The stories that follow are based upon interviews conducted over time with Leadership graduates. The stories illustrate the impact of vision and education first on families and individuals with disabilities—on how parents see their children, how individuals see themselves, and how different decisions result from different beliefs. Secondly, they illustrate the impact the graduates of the Leadership Series have on the systems, policies, and practices of the state—on how students with disabilities are educated, how adults with disabilities are living and working in communities, and how families are supported.

It is the hope that these stories, the information presented in this manual, and the forms in the appendices will be a source of inspiration and motivation to create positive change through leadership development.

"By including everyone without regard to ability or disability, students can learn through experience that belonging is a right, not a privilege that must be earned."

DARE TO DREAM

With Toni Sweedler

Toni Sweedler is the first to admit that she had no expectations of what she would learn from the Leadership Series. "At that point in my life, I was drained of all energy—physically and emotionally. The system had me baffled, bitter and empty. My self-esteem was in the basement and I had lost all sight of what I wanted for my son. When I got accepted to Leadership I thought that maybe I would learn some small thing that would help me feel more in control," she said.

Toni says that what happened to her at Leadership was "just short of miraculous." She discovered "new-found dreams, ideas, and challenges," explaining, "I no longer viewed my son as a burden or someone to apologize for. I learned that it was okay to love him for all of the wonderful things he has to offer—wonderful things I had lost sight of because I had been so busy trying to fix all of the broken parts."

Toni's oldest child, Caleb, is now 15. Toni says that she is now in the "enviable" position of being the mother of three adolescents. "With two sisters in the house, life can be quite overwhelming if you're a boy and you want to get into the bathroom," Toni laughs. "But Caleb approaches it like any boy his age—he yells and bangs on the door! His sisters treat him very much like they would treat anyone—they yell back, get mad, and slam doors!"

Toni wasn't always so calm and accepting in dealing with her family. "For a long time, I had the feeling that things were just not right. I had so many questions about so many hard issues like inclusion, socialization, emerging adolescence, and the future," recounts Toni. "Before I attended the Leadership Series, I didn't know which way to go. I was at the point of reassessing my life—I was asking myself some tough questions about my son, my attitudes regarding my son, and other people's attitudes toward Caleb. I had a lot of questions, but I just couldn't seem to find the answers."

Toni attended the Leadership Series in 1990 and she states, quite emphatically, that it changed her life. She began with burning questions, and left with a clearer understanding of how to find answers. She reflects, "I think the biggest thing I learned was that I *did* know what I wanted for Caleb—it was exactly the same thing that I wanted for all of my children. And once I realized that I knew what was best, I became confident that I could make things happen." For too long Toni had assumed that "professionals knew best" and she had to go along with whatever they recommended. After the Leadership Series, Toni says, "I became more sure of myself. I stopped apologizing and began to speak my mind. And to my surprise, as I spoke, the school district began to listen!"

Today, Caleb is a full time member of his neighborhood school. He has lots of friends, has played on the football and basketball teams, and has challenged and changed everyone's ideas and expectations of him. "He is definitely a typical teenage boy," Toni says. "The only things he talks about are wanting to date and wanting to drive. He also spends a lot of time in front of the mirror fussing and primping to look his best, and that drives his sisters crazy. As you can imagine, there is never a dull moment in our house!" Toni laughs.

Now that things are going well for Caleb, Toni has turned her attention to her community and the state. "Leadership gave me a unique perspective of the larger picture," says Toni. "I have found that getting Caleb included has paved the way for other children in our district to return to their neighborhood schools." Toni states that the building principal has embraced the philosophy of inclusion, and is always encouraging her to include Caleb in activities that she hadn't even thought about.

Toni is extremely community-minded and has incorporated her philosophy of inclusion into all facets of her community involvement. She served three years on the local school board and was able to influence the board to make major policy and educational changes. "It's now a given that kids go into regular education classes. Teachers and staff are beginning to see that there really isn't that much difference between

education for kids with and without disabilities," says Toni. As a director of the Plymouth State Fair, Toni saw to it that all Fair buildings were accessible and that there were "handicapped parking and bathroom facilities." She writes a column in the weekly newspaper and is committed to making sure that issues regarding people with developmental disabilities are always respectfully reported.

Her involvement does not stop at the community level. Toni participated in New Hampshire's Medicare waiver study by interviewing a number of people in the state. She purchased a computer and has become an avid letter writer—expressing her strong opinions to state legislators and policy makers. Toni is making her voice heard around the state.

Toni continues to make her mark in her community and the state, but she is proudest of her ability to "make things happen" for her son. Toni says, "Leadership taught me that it's okay for parents to advocate for their children." Throughout Leadership, Toni listened and spoke to many parents who had achieved positive outcomes for their families. Many of these parents "spoke of the balance of knowing when to push and when to pull back—but never backing down on what you know is right," Toni remembers. "After Leadership, I went home and timidly tried out my new skills on my special education director. I told her what I wanted and to my surprise she said 'yes.' Leadership taught me that I'm important, and I count—and my kid is okay too!"

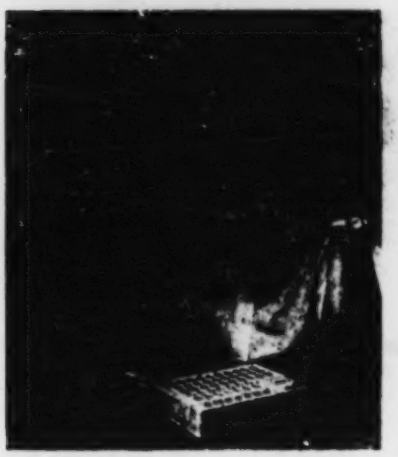
"The Leadership Series," Toni says, "was one of the most exciting and important things that has happened for me. I think Leadership should be renamed 'Dare to Dream' because that is what it made me do—I had forgotten how."

"Between the knowledge and the friendship, it's a great experience."

IT'S A WHOLE NEW WORLD

With Janet Williamson

Janet Williamson has three sons. Her eldest, Jeff, is 22 and is one of the first students with severe disabilities to graduate from high school in New Hampshire. Jeff graduated from West High School in Manchester in 1992 and now works at a health care center. Jeff enjoys his new job, takes aerobics classes at the YMCA, and successfully manages the people who provide assistance to him at home and on the job. Janet Williamson is a strong, determined, and loving mother who takes none of Jeff's accomplishments for granted. She now plays an active part in seeing that her son—and the daughters and sons of all parents—get what they need and what they deserve.



Beginning in 1989, the Williamsons went through three years of due process hearings (involving three appeals by the school district) to get Jeff included in his neighborhood school. This process, which was lengthy, painful, and frustrating, was unfortunately necessary in order for Jeff to achieve his rightful place in society. "I never wanted a fight," says Janet, "but once I knew what I wanted for Jeff, I wasn't going to stop trying until I got it." Deciding what she wanted for Jeff was a direct result of her participation in the very first Leadership Series in 1988. "Before Leadership, I knew Jeff needed and deserved more, but I just wasn't sure what was best. I went to the Leadership Series hoping it would give me some ideas on what Jeff's education should be like. I thought maybe I'd get a few suggestions and maybe be able to make a few changes. What Janet soon discovered was that her participation in the Leadership Series would change her life.

Janet, who now works for the Institute on Disability's Technology Partnership Project, is an extremely strong advocate of parental involvement in education. As a result of Leadership, Janet says "I have learned that when children are young, parents must be in charge of the way services are provided for their children—the professionals should not be calling the shots. Of course as your son or daughter grows older, he or she then needs to be in control." Janet tells parents to "have a vision for your child and to work with the school system to achieve that vision." Now that her son is an adult, she notes that "Jeff and I work together to get a clear picture of what he wants and how he'll get there."

Janet says that Jeff's life has changed as a result of her participation in Leadership. "Jeff has grown and blossomed in the last few years. He used to be an angry and self-abusive teenager and now people describe him as loving, sociable, and friendly. Jeff talks more, looks taller, is hard-working, and eager to learn. He has a great deal of pride in himself and in what he does. And he now communicates through facilitated communication and is able to tell us exactly what he wants from life," Janet says with excitement.

Janet doesn't dwell on the difficulty she had in coming to an agreement with the school about Jeff's education. She is quick to point out that because of Jeff, "our school district is no longer totally segregated. Slowly, they are including more and more children in their neighborhood schools." Janet is proud of her family's efforts to have Jeff attend high school and hopes that they have made it easier for other parents to achieve full inclusion for their children.

Advocating for change does not stop with Jeff. Janet has taken part in a number of panel presentations—addressing professionals and parents

about her experiences, and how she supports Jeff to reach his goals. Although still nervous about speaking in front of a group, Janet knows that her family's story can inspire others to create positive change for all people with disabilities. "During Leadership I learned from other parents how important inclusion is for all people," she says. Now, Janet feels it is her turn to teach others.

Janet believes that parent education is essential to help parents achieve positive outcomes for their children. "Leadership has been critical to Jeff's success, and I believe this training should be available to all families," Janet says emphatically. Carefully choosing her words, she adds, "every professional in our life has some type of degree and access to ongoing training, yet parents, who live with the outcomes of every decision, often remain in the dark." Janet says, thanks to the New Hampshire Leadership Series, she now understands the system. "I believe that the more parents know, the less time and money is wasted on decisions made by people who do not know the family or the child."

Janet describes Leadership's impact as profound. "It gave me confidence and strength in my beliefs, " she says smiling, "and I've begun dreaming again. The effect of Leadership is very difficult to put into words, but all of the graduates I know have made dramatic changes in their children's lives and in the way professionals treat parents. It's a whole new world for the young children in New Hampshire, and a lot of it has to do with the Leadership Series."

"The information learned, the friendships made, and the feeling of power is amazing!"

THE SKY IS THE LIMIT

With Marlyn Curtin

If ever there was an example of a popular teenager, it is Jocelyn Curtin. She has many friends and is involved in countless school and after-school activities. Included in regular education for the past five years ("and every year gets better," says her mother, Marlyn), Jocelyn is now in ninth grade. Marlyn credits the New Hampshire Leadership Series with "allowing me to dare to dream and plan for my daughter's future. Now I know the possibilities for Jocelyn just don't stop!"

Marlyn reels off a list of Jocelyn's interests and activities: "She's joined the Girl Scouts, has gone to the Boys and Girls Club, spent a week at an environmental camp with her class, spends the summer doing fun things with her friends, takes riding lessons, goes on the City Park and Recreation trips." At this point, Marlyn interrupts herself to make sure it's understood that Jocelyn goes on these trips with her friends, not with a paid assistant. Then, she proudly continues the list: "This year, at the

request of a friend, she joined CCD class at the local church and was able to make her First Communion. Early next year she's going to be a junior bridesmaid in a wedding—the bride is *her* friend first, a family friend second."

All of this began after Marlyn attended the New Hampshire Leadership Series in 1988. "The series and its participants energized me. Immediately after the first session, I contacted the school to begin the process of fully including Jocelyn," said Marlyn. Up to that point, Jocelyn had attended a self-contained classroom for children with disabilities and Marlyn believed that was all Jocelyn could do. As Marlyn reflects on that time she grows more pensive and says, "Before Leadership, I had incredibly low expectations for Jocelyn. I believed all of the professionals who told me that Jocelyn would never succeed in the real world." Marlyn continues, "At that time, my biggest hope for Jocelyn was that someday she might be able to live in a group home! That was as high as I dared to dream. Now, I know that the sky is the limit! Jocelyn can do and be anything she wants. Recently, her friends were talking about where they would live in the future and they thought that Jocelyn would want to live in her own apartment with her friends. I agree!"

Marlyn's life is just as busy as Jocelyn's, and she says that Leadership was the "giant stepping stone" to her involvement in local and state politics. Marlyn keeps up to date on all school and legislative issues and has testified at numerous public hearings on issues of family support and education. She has served on the local Family Support Council and is currently working with the New Hampshire Parent-to-Parent Network, offering supports and information to parents in the Concord area. In order to keep the flow of current information going, Marlyn started a statewide Rett Syndrome support network. She is passionate about inclusive summer experiences for children and works with the local school district and area agency to ensure that everyone can have these opportunities. Marlyn has become one of the strongest forces in the state on the issue of friendships for people with and without disabilities and is frequently asked to speak on this topic. Marlyn is certainly no stranger to struggle, but views life in a very positive fashion. " *Everything* takes effort," she says, "but I look at problems as challenges instead of obstacles."

In recounting the high expectations she now has for Jocelyn, Marlyn remembers a conference many years ago. "I can remember listening to parents describe how their kids with disabilities attended regular classes. I thought, this is great for other kids, but it would never work for Jocelyn. I thought that Jocelyn was 'much too disabled' to have the kind of life

these parents were talking about." The Leadership Series "showed me a picture of a positive future for my daughter, and gave me permission to dream." Most importantly, Marlyn says, "it gave me the self-confidence, resources, and support to make my dreams come true.

THE TAPESTRY OF LIFE

With Sandy Whipple

Sandy Whipple is the mother of two talented daughters, Erin who is 12, and Amanda, who is 6. Some 20 years ago, as a college student, Sandy worked at a state institution and says she "witnessed, first hand, man's inhumanity toward man." She says she knows deep in her heart that "we must never allow even one human being to return from where we have come."

Sandy attended Leadership in 1990. It was part of her quest for the best possible life for her daughter. "Thanks to what I learned from the speakers and participants at Leadership, Erin is now a full time member of her neighborhood school and is well established in the academic and social realms of her life." Sandy said she views the experiences and contacts she made at the Leadership Series as "a kind of bank account or insurance policy to be tapped when and if necessary," says Sandy. "On more than one occasion, the contacts I made at Leadership provided me with the information and support necessary to get through the day a little easier."

When asked to speak of the impact Leadership had on her life, and on Erin's, Sandy speaks of Erin's remarkable achievements. These are possible, she says, "because Family Leadership gave me the knowledge and the skills to do what I always knew was right." Here is, in her own words, what Sandy Whipple says about her daughter and the New Hampshire Leadership Series:

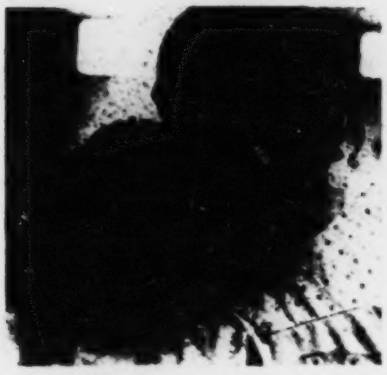
Erin recently played hostess to seven friends at her birthday party. She takes saxophone lessons, has participated in three school plays, and loves animals. Her dream is to become a veterinarian's assistant and live on a huge farm. She will be going to her first boy/girl dance this fall. She is very confident and self-assured and has a very sophisticated sense of humor. She also happens to have a label of mental retardation, with Attention Deficit Disorder, speech and language impairment, fine and gross motor delays, and visual/perceptual problems.

"Erin spent four years in a segregated, out-of-district placement. I knew in my heart that this wasn't right and that she needed to be with lots of different kids. When she was younger she had been in a typical play group and she loved it. So, I slowly began to get myself educated. I

"The 'Home of your Own' session really changed my mind set for my daughter. I realized that she could have a home if she desires and that she doesn't have to be part of the group home experience."

attended Family Leadership and heard about this 'novel' idea of kids with disabilities going to school in regular classrooms with their peers. Immediately, I knew I could make this happen for Erin. After gathering as much information as I could to support myself, I approached the principal of our neighborhood school requesting that Erin be enrolled in this school. Much to my surprise, the principal agreed wholeheartedly. The rest, so they say, is history.

"Erin is a pioneer of sorts, as she is the first student with severe disabilities who has been "returned" to our neighborhood school. Her success has paved the way for others to return to regular classrooms with their peers. Her courage, strength, determination and spirit are inspirational to many.



"There is so much to say about Erin. She is living proof that once the imposed barriers, limitations, and lowered expectations are removed, the human spirit knows no bounds. I have no doubt that she will accomplish much in her life. Perhaps her greatest gift has already been realized—she has helped many to see more clearly the intricately-woven tapestry of life."

Just as Erin is a pioneer, so too is Sandy. Sandy is an outspoken and busy advocate for inclusion. Last year, she spoke at the New Hampshire Family Support Conference. Feeling that "words don't always do justice to some situations," Sandy made a video to tell the story about inclusion at Erin's school. The video was very well received, and she has since shown it to her school board, other school districts, and the board of a local private preschool. Most importantly, Sandy's video is shown to all parents and children entering their neighborhood school.

Sandy is the newly elected co-president of the PTA. High on the list of the group's priorities this year is updating the school's playground—and Sandy will make sure that it will be "safe, fun and accessible." Sandy admits that though she exposes Erin to many different things, she is like most other parents when it comes to letting go. "In my zeal to protect Erin, I tend to forget that there is dignity in failure," she says. She takes special pride in knowing that both her daughters are compassionate and caring people, and hopes that they will grow to appreciate the differences in everyone. Sandy says, "I know that Leadership made a difference in my life, and every time I look at Erin I can see the difference it made in her life."

I HAD NO IDEA WHAT I WAS IN FOR

With Alice Porembski

As the mother of seven children, Alice Porembski is seldom surprised. "But, I had no idea what I was in for," she says of her experience in the New Hampshire Leadership Series in 1990. "Corey was only two years old and I was interested and eager to take some action that would help me move forward with my grief. I was also anxious for the opportunity to meet other parents and to see first hand what attitudes and conventional wisdom were around the state." What Alice expected from the Leadership Series was interesting speeches and a pleasant environment. What she got, she says, "was so much more."

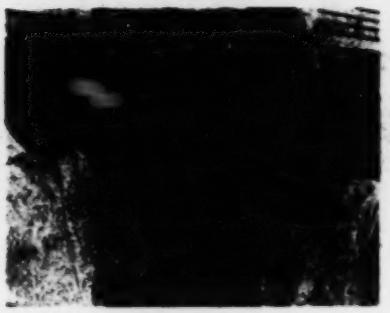
Corey, now 5, is Alice's seventh child; the children range in age from 5 to 22. Although Alice admits she grieved when Corey was diagnosed with Down Syndrome, she notes that her other six children always saw "the sameness" of Corey even when she and her husband, Chuck, saw him as different. Our children have always shown us so clearly who Corey is," she says, smiling. "After Corey's birth, his brothers and sisters were quick to point out his needs. To our surprise, they were the needs of any child—to be held, changed, nurtured, and loved. How often I heard, 'He's just a baby, Mom. Do what you did for all of us.' Because our children saw Corey as 'normal' first, and needing a little extra help second, my husband and I began to see things this way also." The ability of her other children to be "natural facilitators" helped Alice to see *Corey* in a different light. Attending the Leadership Series helped her to see ***the world*** in a whole new light.

"Empowerment" is a word Alice uses often. As a result of Leadership, Alice says she feels "connected, empowered, and more knowledgeable about politics, social roles, power, and parenting. I have testified at legislative hearings, and have organized informal meetings to educate state legislators on disability related issues. I now work as a Parent-to-Parent Coordinator, which gives me the opportunity to support other parents in the state by sharing my knowledge, experiences, and beliefs with them." Alice talks to civic groups and helps parents form support groups around specific issues. She worked closely to help a candidate, who understood and supported inclusive education, get elected to the school board. Alice also points out that she has "educated my extended family—more than they ever wanted to be—on disability and prejudice."

The Leadership Series, Alice explains, "was the most challenging, exhausting, exhilarating, thought-provoking, attitude changing,

"More people should be educated about the accessibility of our legislators and that affecting change at the state level is not out of our hands."

confidence building, peer bonding, surprise laden experience I have ever had." She learned that "there are no pat answers, and creativity and common sense together solve more dilemmas than legal expertise or graduate level degrees ever will!" Through Leadership, Alice said she "found the difference between power and domination," and in listening to other parents, "I experienced courage, shared anger, and rejoiced in the triumph of the human spirit." Alice identifies a common bond with others she met at Leadership—"a bond that reaches far beyond disability and attitudes, into the place where human dignity and value for life reside."



Alice's participation in the Leadership Series led to significant changes in the attitudes and practices of the entire Porembski family. She is proud that all of her children have become advocates for community inclusion and human justice. Her oldest daughter, Ann, age 22, provides respite for college-age persons with disabilities and has developed her college curriculum to better understand the sociological impact of a disability. Oldest son, Chris, age 17, recognized the inaccessibility of the function hall at his Boy Scout Camp and built a ramp to the building. Mark, age 15, is an "after school companion" to a 14-year-old boy with Down syndrome. And Corey spends his days at preschool, playing with friends, and comes home to his large and loving family. Corey shares in the household chores, helping with the laundry and bringing in the mail. While Alice expected to enjoy her six days at Leadership, she never expected that those days would change her life forever.

FROM DISILLUSIONMENT TO DETERMINATION

With Joseph Bauer

Hearing Joseph Bauer tell his story is at once overwhelming and inspiring. Joseph and his wife, Gloryann, exhausted the services in two states before moving to New Hampshire and finding what they wanted for their son, Joe.

The Bauers raised their three children—Lizbeth, Mary, and Joe, Jr., in upstate New York. "We had become disillusioned with the resources that were available for Joe in New York. Joe's early experiences preceded the federal 'right to education' laws and Joe spent his educational career in segregated classes in church basements and other hidden-away places. When Joe was 18, we said 'enough of crayons and coloring books' and at age 18, we pulled him out of school. For all intents and purposes, Joe went from what amounted to kindergarten to a sheltered workshop."

Joseph says, "We found out quickly that the term 'sheltered workshop' glosses over the reality of what it is—total segregation and the daily death of the soul." He goes on with his family's story about selling their

home and most of their possessions and moving to Arizona, where, through a close family friend, they had located what they thought would be "a marvelous, empathetic service" for Joe. After five years in Arizona, Joe was still a participant in a totally segregated day program. The Bauers acknowledge "we became sadly disillusioned when we realized there was no future in this for Joe and had to face the fact that we had made a serious error." The Bauers' daughter, Lizbeth, lived in Manchester, New Hampshire, and encouraged her parents to move near her. It was a move they initially regretted—until Leadership came into their lives.

In New Hampshire, Joe was enrolled in a day program and was later, as his father recalls, "promoted to a sheltered workshop." Joseph Bauer, ever an activist, knew something had to be done to improve the quality of what was being offered to his son. He became involved with local parents of adult sons and daughters with developmental disabilities and eventually formed a chapter of the New Hampshire ARC. That involvement led to his nomination for the first Leadership Series.

"The Leadership Series," Joseph said, "made me realize that I had allowed myself—and Joe—to be brow beaten by professionals in three different states. I realized that we had passively accepted the crusts and crumbs that the so-called experts had handed to us throughout the years.

As a result of his experiences in Leadership, everything began to change. Joseph says, "I realized that I was the one who needed the help to identify, develop, and support our son's positive attributes." Joseph's commitment grew throughout the Leadership Series. He vowed "that no professional would ever again take over the planning and decision making in our son's life. We—Joe and the family—could and would be the ones to call the shots." Meeting with other parents and hearing their stories of determination and success "was more than encouraging," Joseph says. "The speakers and presenters at the Leadership Series were positive, encouraging and dynamic. As a result, I became more meaningfully involved with other parents, both locally and at the state level." Joseph began presenting to legislative committees and public hearings. He organized telephone networks, took part in numerous letter-writing campaigns, and encouraged other parents to take a more active role.

Joe's life has changed as a result of his dad's participation in the Leadership Series. "Joe got his first job in 1989, working in a small bakery," says his father, "He has learned to make use of typical community services, including riding the bus back and forth to work." Joseph proudly recounts one particular story, "In order to get to work, Joe had to cross an intersection filled with cars. After his first solo trip across the street, he

"Not only did we get information but had opportunities to practice strategies to reach our dreams for our children and ourselves."

confidently flashed a thumbs up victory signal. I can't help but think that the drivers of those cars were completely unaware that the universe had just expanded a little bit right before their eyes."

Joseph Bauer is now a highly sought-after speaker—especially to young parents. He shares the knowledge and beliefs that he learned through the Leadership Series with others throughout the state. "Contrary to what many believe, parents can exert a very special kind of influence. Don't underestimate the power of parents and families," Joseph says. "We have contributions to make that are unique. If we allow ourselves to feel helpless, that is what we will become." Leadership, he says, "is the road to the kinds of hope and vision we all need." For the Bauer family, those roads crisscrossed the United States and led them to New Hampshire where, with energy and determination, a whole new life was created for each family member.

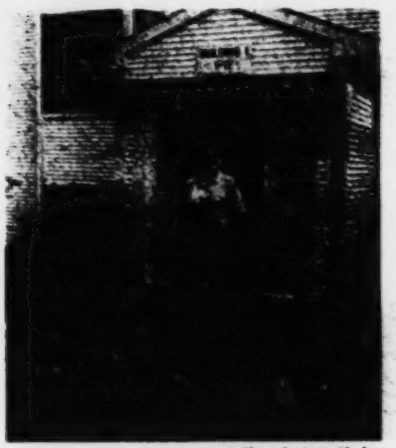


Photo by Jean Clarke

PROVING THEM WRONG

With Jocelyn Gallant

My name is Jocelyn Gallant. I used to live at Laconia State School. I went there on October 27, 1956. I was four years old. I left when I was 27.

They called that place a school but they didn't teach me much. I went to school there for 23 and a half years. Conditions were bad. It was a terrible place to live and grow up. The first place I lived was called Keyes Two. There were 125 beds on that ward. It was very noisy at night. I can remember being very scared. All of the residents were bigger than me. I was only four years old at the time. Residents didn't always keep their clothes on and sometimes they messed on the floor. It smelled bad and I was embarrassed.

People hit me while I lived there. Sometimes it was the residents. Sometimes it was the staff. People were always getting hurt in the state school.

At Laconia, I didn't learn to read. They said I couldn't do it. They didn't want to show me how to tell time. They said I wasn't smart enough. They didn't want to teach me anything. What kind of school doesn't teach you anything?

When I left Laconia 16 years ago, I had never mailed a letter. I couldn't make change from a dollar. I never had a checking account or paid bills. I couldn't cook or do laundry.

Most of what I know today I have learned since I left the state school.

When I first left Laconia I went to live in a group home. It was better than the state school, but it was still like a prison. The difference was you could stay up past nine o'clock. You had to stay in your room but you didn't have to go to bed.

How many twenty seven year olds have to go their room at nine o'clock?

They did have classes at the group home. I learned to read and make change.

Then I went to a shared home. I lived with very nice people but I didn't learn all that much. After that I went to a supervised apartment. Everywhere I lived there were too many rules to follow. Rules that most people don't have to follow. It was hard.

Now I have my own apartment. Last summer I planted my very first garden. I wrote a letter to my landlord to get permission. I bought the seeds I needed to grow vegetables with and paid with my own money. I have a job as an office receptionist. I attend adult education classes. I have a clothesline and a gas grill. I have a checking account and pay my own bills. I take organ lessons. I do photography as a hobby. I have my own friends. I am learning how to be a good home cook. I learn new recipes all the time.

I stay up past nine o'clock.

New Hampshire Leadership helped me to advocate for my rights and help other people feel that they belong in the community like everyone else. But there is still more to be done. I still want to be able to choose my own services. I don't want some agency choosing for me. I made a lot of progress in my life. Most of the progress I made was on my own.

Here is what people need. They need control over their services. They need transportation. They need to go to regular schools and learn in regular classes. They need more opportunities and less agencies.

The agencies are growing not people with disabilities. The money should go to the people. Let people decide how to spend the money. All my life I heard people tell me I can't do things. All my life I have been proving them wrong.

"Leadership lit my soul on fire. The laughter is back where it belongs—in my home with my family!"

NEW HAMPSHIRE LEADERSHIP TURNED OUR LIVES AROUND

With Linda Steir

Linda Steir and her beautiful daughter, Marika, recently flew halfway around the globe to lecture about full inclusion in seven cities in Japan. Linda believes this is just the tip of the iceberg as she embarks on a very fulfilling career as the Family Support Coordinator for one of New Hampshire's regional agencies.

How did this come about? "Leadership," Linda says, without hesitation. "The Series taught me that it was okay to expect a better, more typical education for my daughter. It taught me to feel more positive about having a child with a disability instead of feeling isolated and at the mercy of systems, and the professionals who run the systems."

NH Leadership Turned
Our Lives Around

Linda took part in the Leadership Series when Marika was 3. "In my heart, I knew that I had to find out what was out there before I could start making choices about what would work or wouldn't work for my daughter," she says. Linda was aware of the work being done in the state around inclusive education, family support, and leadership development and wanted to learn more. "I had met other parents who took the Leadership Series and they were confident advocates—secure in their roles as parents of children with disabilities. I wanted to share in the enthusiasm I saw them applying to their child and family."

"High expectations for Marika" is Linda's immediate response when asked what her family gained from her participation in the 1990 Leadership Series. "We now know that Marika can do and be anything she wants." says Linda. As a Family Support Coordinator, Linda is asked to run local, regional, state, and national workshops about family support systems. Linda's three-week trip to Japan, accompanied by representatives from the Division of Mental Heath and Developmental Services, helped people from Japan "understand why full inclusion is so important and effective. The lectures were intended to motivate the Japanese to work toward de-institutionalization and community integration." A year after the lecture tour, Linda and Marika still get letters of appreciation from people they met in Japan.

"The Leadership Series," says Linda, "taught me to advocate for full inclusion." She knows, too, that an important part of teaching others is self learning. "I have become assertive and proud in my community. I have earned the respect of my peers who do not have children with disabilities. My daughter has been photographed on numerous occasions for local papers in very positive, inclusive situations. I feel equal to my peers in the community."

Linda and her family traveled a difficult route to get to where they are today. Before Leadership, Marika attended a self contained, segregated preschool program for children with various disabilities. It took almost two years to get Marika included in a typical kindergarten, a struggle that Linda calls "incredibly difficult and draining for me and for my entire family. We nearly abandoned the process several times, but our strength to be persistent came from the professionals and parents we had met during Leadership. Much of our courage and perseverance came from knowing people who shared our vision and supported our struggle."

The struggle was worth it, Linda says, as she talks about Marika, who is now in second grade and goes skiing and to summer camp. "We've learned that nothing is impossible for our daughter." The entire family

advocates for people with disabilities, Linda says, including Marika's brother, Morgan, age 8, "who scolds people who illegally park in handicap spots, and who advocates for elderly people in need of additional supports and understanding." The family's "changed attitudes," Linda adds, "have carried over to our extended family who we have taught to use respectful language when talking about people with disabilities. They now expect a lot more from their communities in terms of accessibility and employment of people with disabilities." Linda credits the "high expectations and vision we have for Marika" as the motivating forces for her family and others in the community.

Linda points to four reasons why she encourages others to become involved in Leadership. "Become part of the Leadership Series," she says, "if you want to know where or how to begin to feel good about the future of your child and family; if you've ever felt rejected by friends or schools or society; if you've ever been at a loss for where to turn to get information or support; and if you've ever wondered what you can do as one small voice to make an entire system change." Family Leadership "taught us that we will never be alone or lonely," Linda says. "After three years of fear and isolation, the Leadership Series turned our lives around."

"I have seen people blossom here. I have watched anger turn into action and people learn about ways to affect change in a constructive way."

Afterword

by Beth Dixon

Seven years ago, my life changed in a very dramatic way. For the first time since my son, Andrew, was born, I was surrounded by people who allowed—no, inspired—me to think positively about the future. The Leadership Series gave me the strength and the commitment to change my family's life, and the lives of people all over the state and the country.

The stories you have read reflect the personal journeys of eight graduates of the New Hampshire Leadership Series. Although each family is unique, all of these stories profoundly illustrate the common themes of the Leadership Series—a dedication to the ideals of inclusion, the power of new-found skills, the confidence that comes from knowledge, and the celebration of the abilities of all people. Each story expresses, in its own way, each person's metamorphosis from vulnerability, acceptance, and frustration, to power, leadership, and hope.

The families represented in this book are but a handful of the many families who have participated in the Leadership Series. Unfortunately, there is not room for everyone's story to be told in this manual.

The effects of the Leadership Series do not stop with the person who attended the Series. Each graduate has extended his or her energy, insight, and enthusiasm to others, and the reverberations are felt in homes, schools, and communities throughout New Hampshire, the country, and as far away as Japan.

The outcomes of Leadership are many. In response to the requests of Leadership graduates, many neighborhood schools and regular classrooms have opened their doors to students with disabilities. Community organizations and school boards have invited graduates to speak about the values of inclusion. At the state level, graduates have successfully lobbied for the passage of several state bills designed to increase family support in New Hampshire. For some graduates, careers have changed as a result of new skills and abilities, as well as an ever-growing commitment to the belief that all families must have the opportunity to create positive futures for their children.

Being involved with the Leadership Series has inspired me, and many other parents, to become effective advocates for change. But, for me, the most important changes came from within. The Leadership Series taught me to look at my son's life in a different light. I learned that it is more important to support Andrew for who he is than to work to "fix his disabilities." I learned that special isn't always better, and in fact, typical can be quite extraordinary. As I advocated for Andrew to be a member of a regular classroom (in the same school that all of my other children had attended), I learned that "just a parent" is capable of just about anything.

"Before Leadership I had all the pieces but I didn't have the overall structure. I felt like the pawn in chess. Someone else was controlling all the action. Now, I'm the queen of the board!"

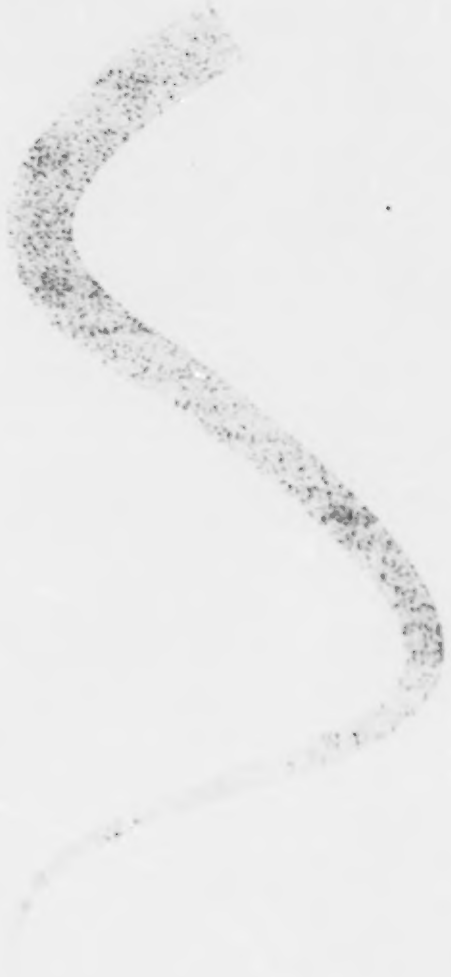
My participation in Leadership changed me, but it also changed each and every member of my family. Both of my daughters have written essays for their application to college that describe their feelings about inclusion, acceptance and the power of families. My youngest daughter, Sarah, writes in her 1993 essay:

> Over the years I have watched Andrew become a respected member of his school by just being himself. Andrew has taught me that it is normal to be different, and it's those differences that make us great. He has taught me that no one is perfect, but everyone is o.k. I have learned from Andrew to respect all people, and that everyone, no matter how they look or act, has a right to their own opinions and feelings. Andrew had opened up my mind immensely.

And that's just what the Leadership Series is all about—opening our minds widely enough to see the future in a new way. I hope that each family will grow, as mine has, a most wonderful vision for the future, and a most celebrated appreciation for today.

Appendix A

NOMINATION PROCESS
FORMS AND LETTERS



"The information regarding negotiations and community organizing was very valuable, not only applicable to negotiating with schools but all facets of life."

BEST COPY AVAILABLE

Dear Friends of Leadership:

The Institute on Disability/UAP, at the University of New Hampshire, is once again requesting your assistance in nominating adults with disabilities and parents of children with disabilities to participate in the New Hampshire Leadership Series. The New Hampshire Leadership Series is seeking participants who are highly motivated to become well informed about, and active in, policymaking and systems change for individuals with disabilities in our state.

The New Hampshire Leadership Series provides participants with state-of-the-art information about issues concerning people with disabilities. Leaders in the field, adults with disabilities, parents, and family members, will present information and facilitate groups during each session.

At the New Hampshire Leadership Series, participants will receive a wide range of information and strategies designed to assist them in setting visions and achieving dreams for themselves and their families. The New Hampshire Leadership Series will educate families and adults with disabilities about best practices in education (including secondary and post secondary education), employment, housing, and participation as full members of the community. In addition, information on positive approaches to challenging behavior, assistive technology, negotiation skills, the history of the disability movement, community organizing, and the legislative process will be addressed.

This Series provides participants with overnight accommodations and all are encouraged to take advantage of the opportunity to network with each other "after hours." Six two-day sessions will take place monthly. The people selected must commit to participation in all six sessions.

Participants are provided with financial support to cover all expenses, including materials, lodging, meals, and child care. Participants will be selected on the basis of: 1) their interest; 2) their ability to organize other community members; 3) their commitment to attend all of the sessions in the Series; and 4) geographical location with the state.

Enclosed, please find a nomination form to complete and return to us. It is not necessary for you to contact possible participants. When we receive your nominations we will send a letter explaining the New Hampshire Leadership Series and an application to all who are nominated. There is a selection process and only 30 participants will be chosen.

The deadline for nominations is (date).

If you have any questions or would like further information, please feel free to call me at 228-2084. Thanks very much for your help.

Sincerely,

Beth Dixon
Leadership Coordinator

Enclosure

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PARTICIPANT NOMINATION FORM
NEW HAMPSHIRE LEADERSHIP SERIES

The following people are nominated for the Leadership Series by:

_____
(Name, Address, Telephone)

NAME _____
ADDRESS _____
TELEPHONE _____
COMMENTS _____

NAME _____
ADDRESS _____
TELEPHONE _____
COMMENTS _____

NAME _____
ADDRESS _____
TELEPHONE _____
COMMENTS _____

NAME _____
ADDRESS _____
TELEPHONE _____
COMMENTS _____

Please complete and return to:

Beth Dixon
Institute on Disability/UAP
Unit 14, 10 Ferry Street
The Concord Center
Concord, NH 03301

For more information call: 228-2084

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Appendix B

LETTER OF INTRODUCTION
AND APPLICATION FORM

"Having attended the legislative session, I am absolutely sure my actions will change. I intend to be a truly informed person—not only for personal concerns, but also for community education. My intention is to be known as a contact—one who knows!"

Dear (Personalize),

You have been nominated by (personalize) to participate in the Institute on Disability/UAP's New Hampshire Leadership Series.

We are actively seeking highly motivated men and women to participate in the New Hampshire Leadership Series. This Series is a leadership training program for individuals with disabilities and parents who have children with disabilities. It provides state-of-the-art knowledge about disability issues and has a broad based and ambitious curriculum. Participants come together for six, two-day sessions and receive intensive education on a wide variety of educational and leadership issues.

Each session of the Leadership Series combines education and experience. Professionals in the field, parents, and consumers join together to provide participants with useful information and effective strategies for achieving successful outcomes for themselves, their families, their communities, and the state.

In general, session topics will include:

- History - Independent living movement, parent movement, self advocacy movement, and family support
- Creating a vision for yourself and/or your family
- Inclusive education and positive approaches to behavior management
- Supported living, naturally supported employment, futures planning, inclusive communities
- Assistive technology, health care issues
- State and federal policy and legislative issues
- Community organizing, advocacy organizing, negotiation skills, facilitating meetings

The New Hampshire Leadership Series is a collaborative project with funding and support provided by a wide variety of local and state agencies. In addition to financial support, representatives from these agencies are involved in the nomination, application, and selection process for participants. Many are also involved as presenters or group facilitators.

There is no cost to participants. Financial support is provided for child care/respite, mileage to and from the Series, lodging, meals, and materials. People needing additional supports (e.g., transportation, interpreter, physical assistance) will be assisted in every way possible to facilitate their attendance. In return for these supports, participants are asked to make a commitment to attend and participate in ALL SESSIONS and to complete all homework assignments.

The location for this year's Series is (place). Each session will begin at 1:00PM on Friday and end at 4:00PM on Saturday. Most will include Friday evening workshops so attendees are requested to stay overnight at the hotel. The following dates have been selected for the sessions:

Session 1 (date)
Session II (date)
Session III (date)
Session IV (date)
Session V (date)
Session VI (date)

We are particularly eager that members of the group represent diverse backgrounds, ages, and different geographic regions of the state. The applications will go to a selection committee that will choose 30 participants based on their application and the above criteria.

Enclosed, please find an application for participation in the New Hampshire Leadership Series to be completed and returned in the envelope provided by (date). Participants will be selected on the basis of their degree of motivation to become well informed about, and active in, policymaking and systems change for individuals with disabilities in our state. The application review committee will meet in July. If selected to attend, you will be sent more details soon. If you are not selected this year, your application will be kept on file for next year's Series. I look forward to receiving your application.

Beth Dixon
Leadership Coordinator

P.S. Please feel free to call me at 1-800-238-2048 for more information or additional applications.

APPLICATION FOR THE
NEW HAMPSHIRE LEADERSHIP SERIES

Institute on Disability/UAP
University of New Hampshire

NAME _____
ADDRESS _____
CITY/STATE/ZIP _____
TELEPHONE Daytime Number _____

1. Would you prefer this application in an alternative format (i.e., large print, Braille, personal or telephone interview)? If so, please contact Beth Dixon at 1-800-238-2048.

2. Are you applying as: _____ a parent
   _____ a family member
   _____ a self advocate

3. Tell us a little about:
   a) yourself and your family;

   _____
   _____
   _____
   _____

   b) what you are most proud of;

   _____
   _____
   _____
   _____

   c) your experience in leading others in the achievement of goals e.g. owned your own business, made a change in your community, received an award for volunteering.

   _____
   _____
   _____
   _____

4. What motivates you to apply for this Series and how might it help you or your family? _____

   _____
   _____
   _____
   _____

5. Are you willing and able to make a commitment to attend all 6 workshop sessions? Yes _____ No _____

6. Have you been involved with family or self advocacy groups in the past? Yes _____ No _____
If yes, please describe your involvement.

_____
_____
_____
_____

7. Are there any childcare/respite services or any attendant services you need to participate in the Leadership Series?

_____
_____
_____
_____
_____

8. Are there any accommodations necessary for you to participate in this program (special meals, transportation needs, etc.)? If yes, please describe.

_____
_____
_____
_____

9. Tell us about your involvement in any state agencies, task forces, or committees in your area.

_____
_____
_____
_____

10. If you would care to, please tell us about any special interests, hobbies, etc.

_____
_____
_____
_____

Thank you for your interest in the New Hampshire Leadership Series. Please return your application by (date) to:

Beth Dixon
Institute on Disability/UAP
The Concord Center
10 Ferry Street, Unit 14
Concord, NH 03301

If you have any questions, please call 1-800-238-2048.

Appendix C

LETTERS TO APPLICANTS WHO ARE ACCEPTED AND NOT ACCEPTED INTO THE SERIES

"I learned that I am not alone. I have the power to make choices and the ability to share information with others."

[redacted]

Dear (personalize):

Congratulations!

You have been selected as one of the participants in the New Hampshire Leadership Series. The response was very good and we had a difficult time choosing among so many excellent candidates.

This six-session Series is designed to involve and empower families of children with disabilities and individuals with disabilities in policymaking and systems change. The series is designed to: 1) Introduce you to state-of-the-art opportunities: 2) Provide you with education on current issues in the disability field; and, 3) familiarize you with policymaking and the legislative processes in New Hampshire and nationally.

Enclosed is information on participant responsibilities to be completed and returned A.S.A.P. to confirm your attendance.

Please note that participation in this Series requires a time commitment of six, two-day session beginning on (date). This session and overnight accommodations will be held at (location). Please read the enclosed materials carefully. To reserve your place in the Series, sign the attached agreement and mail it back using the enclosed envelope.

If you have any questions or need more information, please call me at 228-2084 or 1-800-238-2048.

Again, congratulations on being selected to participate in this unique and exciting opportunity! We look forward to meeting you!

Sincerely,

Beth Dixon
Leadership Coordinator

Enclosure

Dear (personalize):

Thank you very much for your interest in attending the New Hampshire Leadership Series. As you can imagine, we had an overwhelming number of applications from family members and individuals with disabilities interested in participating in this unique opportunity.

Choosing the 30 participants to attend the Series was a difficult process. All of the applications demonstrated interest and motivation to learn about state-of-the-art practices, policymaking, and community organizing strategies for people with disabilities. Decisions were made based on application content, location, and diversity of age and disability.

Although you were not chosen to participate in the (year) Leadership Series, hopefully the opportunity will present itself next year and you will still be interested in attending. We would like to keep your application on file in order to inform you about upcoming Institute of Disability sponsored events. We are exploring the possibility of offering some additional training to those of you who may be interested.

Once again, thank you for your interest.

Sincerely,

Beth Dixon
Leadership Coordinator

Appendix D

CONFIRMATION FORMS AND CONTRACTS

"I learned how important it is for us all to stick together and fight as a whole. The Legislative session was really educational for me."

Hello Leadership Participants!

The final arrangements are being made for this year's Series and we will all meet next week!
The first session will begin promptly at 1 PM on Friday afternoon, (date). Check-in time at the hotel is 2 PM, but you will be able to check in at 12 noon if your room has been cleaned. There will be a registration table in the hallway to register for Leadership and a lunch buffet will be available.

An agenda is enclosed, as well as directions to the hotel. There is a parking garage under the hotel and, if it is full, there is valet parking available in front of the hotel.

Please dress casually and as comfortably as you wish. Remember, you may want a walk on the beach so bring something warm! There is also an indoor pool if you find time to use it.

Travel and respite reimbursement forms will be given to you to sign and return to me before you leave. Processing them takes a few weeks, but you will not be forgotten!

That's it for details. If you have any questions or concerns, call me at 228-2084 or 1-800-238-2048.

See you Friday around noon!!!

Beth Dixon
Leadership Coordinator

LEADERSHIP SERIES CONFIRMATION FORM

I understand that, as a participant, I will be required to:

- Make a time commitment of six, two-day sessions (dates)
- Arrange child care or respite for child(ren) with the understanding that this cost will be reimbursed
- Participate in activities/experiences and complete reading and work between sessions
- Keep track of expenses incurred in order to receive reimbursement

1. ____ Yes. I will be attending the Leadership Series

2. Will you be using respite or childcare? _____ Yes _____ No
   If Yes: approximate cost of care for each session:_____

3. Do you need any accommodations or special meals? _____Yes ____No
   If Yes, please explain _____
   _____

4. A room will be reserved for you. Do you prefer a smoking or non-smoking room? (The hotel will do its best to meet our requests about rooms, but if you require non-smoking for medical reasons you will have priority.)
   _____ Smoking _____ Non-Smoking

5. Other comments/requests?
   _____
   _____
   _____
   _____

Name _____

Reservations must be received as soon as possible. Thanks!

LEADERSHIP SERIES CONTRACT

As a participant in the **Leadership Series**, I understand and agree to the following:

To be present at all two-day sessions.

To participate fully in the sessions - interacting, questioning, reporting.

To complete assignments (attend meetings, read, write, telephone) between sessions.

To demonstrate competencies through actions (letters, articles testimony, appearances, meetings, phone calls).

To communicate with other participants in the program, with a partner/mentor and with the coordinator regarding issues, ideas, and insights about the program.

To meet formally with a policymaker at the local, state, or federal level to discussions and share information about current issues in the field of disabilities identified or clarified through participations in the program.

_____ _____

Participant's Signature Date

The **Leadership Series** agrees to the following:

To provide, face-to-face, the most up-to-date information from respected and well-known leaders in the field of disability.

To provide reading material, suggestions, and resources to familiarize you with a wide range of topics related to disability and with information specific to your area of interest.

To provide experiences at the local, state, and federal levels to assist you in influencing public policy.

To cover your expenses in the program to the fullest extent possible in return for your complete participations.

_____ _____

Project Coordinator's Signature Date

Appendix E

SESSION AGENDAS

"I am trying to educate people in my community so my daughter can be accepted more and we can be more publicly included—and I'm going to make our goals come true—no matter what's in the way!"

Agenda

SESSION I:
Developing the Vision

12:00 - 1:00	Registration, check-in and refreshments
1:00 - 1:15	Welcome!! Jan Nisbet, Director, Institute on Disability/UAP
1:15 - 2:00	Introductions & Expectations
2:00 - 3:00	Parent Panel: Lois Pincince Joe Bauer Barbara Fenderson
3:00 - 3:15	Break
3:15 - 3:30	"First Impressions"
3:30 - 5:30	Jeff Strully - Executive Director, Jay Nolan, Community Services, LA, Calif., and—a parent!
5:30 - 7:00	Dinner at the Ashworth
7:00 - 8:00	Patrick Worth - People First, Toronto, Canada
8:00 - 9:00	Oceanside Chat with Presenters: two groups

Agenda

SESSION I, DAY TWO:
Developing the Vision

7:30 - 8:30	Breakfast Buffet
8:30 - 9:30	Small Group Session:
9:30 - 11:30	More from Jeff and Patrick
11:30 - 12:15	Small Group - Create a Vision
2:15 - 1:30	Lunch
1:30 - 3:00	Small Groups—Present vision to the large group
3:00 - 4:00	Jeff and Patrick—Closing Comments and Wrap Up

Coming Attractions!!

Exemplary practices in early care, education, positive approaches to challenging behavior, and...direct from Canada...Judith Snow!

Agenda

SESSION II:
Exemplary Practices in Education

12:00 - 1:00	Registration and LUNCH - Portsmouth Room
1:00 - 1:15	"Welcome" - Al Robichaud, Director, NH Developmental Disabilities Council
1:15 - 2:15	Participant Updates
2:15 - 4:15	Exemplary Practices in Education: Ann Dillon, Beth Dixon, Susan Shapiro-Barnard, Institute on Disability/UAP
4:15 - 4:30	Break
4:30 - 6:00	Judith Snow
6:00 - 7:30	Dinner at the Ashworth - Rose Room
7:30 - ??	Meet in Small Groups

Agenda

SESSION II, DAY TWO:
Creating a Path

7:30 - 8:30	Breakfast Buffet
8:30 - 9:30	Small Group Activity
9:30 - 10:30	Judith leads us on the PATH
10:30 - 11:00	Break & Check-Out
11:00 - 12:00	Small Group - Create a PATH
12:00 - 1:00	Lunch - Rose Room
1:00 - 1:30	Small Groups present PATHS
1:30 - 3:00	Herb Lovett - Positive Approaches to Challenging Behavior
3:00 - 4:00	Wrap up with Judith and Herb

Coming Attractions!!

"Home of Your Own" - Jay Klein, "Naturally Supported Employment" - JoAnn Sowers, "Technology" - Richard Dodds,...And More...

Agenda

SESSION III:
Growing Older - Preparing for the Future

12:00 - 1:00	Registration and LUNCH - Exeter Room
1:00 - 1:15	"Welcome"
1:15 - 2:15	Participant Updates
2:15 - 3:00	Leadership Panel: Laura Marko Linda Steir
3:00 - 3:15	Break
3:15 - 5:00	Thinking About Future Careers: JoAnn Sowers, Institute on Disability/UAP
5:00 - 5:15	Break
5:15 - 7:00	High Tech, Low Tech, Why Tech? Richard Dodds, UCPA, New Jersey
7:00 on...	A Leisurely Dinner at the Ashworth

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JoAnn Sowers and Richard Dodds will be with us for dinner. We encourage anyone with specific questions to use the opportunity to join either one for the meal and ask away!

Agenda

SESSION III, DAY TWO:
Growing Older - Preparing for the Future

7:30 - 8:30	Breakfast Buffet
8:30 - 9:30	Small Group Activity
9:30 - 10:30	More "Tech" with Richard
10:30 - 11:00	Break & Check-Out
11:00 - 12:00	Questions and/or Next Steps - Richard
12:00 - 1:00	Lunch - Rose Room
1:00 - 3:00	"A Home of Your Own" - Jay Klein, Institute on Disability/UAP
3:00 - 3:15	Break
3:00 - 4:00	Wrap up with Jay

Agenda

SESSION IV:
Negotiation and Collaboration

12:00 - 1:00	Registration and LUNCH - Exeter Room
1:00 - 1:15	"Welcome" - Robert Kennedy, Director, Division of Educational Improvement, Department of Education
1:15 - 1:45	Participant Updates
1:45 - 2:00	Partners in Health - Dottie Bazos, Hood Center for Caregiving Families
2:00 - 3:00	Collaborating with your Physician - Dr. Carl Cooley, Center for Genetics and Child Development, Dartmouth Hitchcock Medical Center
3:00 - 3:15	Dessert Break
3:15 - 5:30	Negotiation Skills and Team Building Dr. Howard Muscott, Rivier College
5:30 - 5:45	Appetizer Break
5:45 - 6:30	More from Howard
6:30 - 7:30	Speaking Out - Sharissa Kochmeister
7:30 on...	Enjoy Dinner and Conversation in the Rose Room

Agenda

SESSION IV, DAY TWO:
Negotiation and Collaboration

7:30 - 8:30	Breakfast in the Exeter Room
8:30 - 10:00	Small Group Activity (homework review)
10:00 - 11:00	More from Sharissa
11:00 - 11:30	Break & Check-Out
11:30 - 12:30	Leadership Panel: Margie Pearson Maureen Guy
12:30 - 2:00	Lunch - Rose Room
2:00 - 3:30	The Dream Continues - Susan Shapiro-Barnard, Institute on Disability/UAP
3:30 - 4:00	Wrap up and Homework Assignments

Coming Attractions:

Allan Bergman, United Cerebral Palsy Association, using the legislative system to create change.....

Agenda

SESSION V:
Using the Legislative Process to Create Change

10:00 - 11:00	Updates / Homework
11:00 - 12:00	Al Robichaud, Director, Developmental Disabilities Council, "History of Family Support in New Hampshire"
12:00 - 1:30	Lunch
1:30 - 2:30	Allan Bergman - United Cerebral Palsy Association, Washington, DC "The Law and YOU...Why Do Legislative Advocacy: The Legislative Process"
2:30 - 3:30	Joanne Malloy, Institute on Disability/UAP "New Hampshire Legislature: A Status Report"
3:30 - 3:50	Break
3:50 - 5:00	"The Evolution of Common Sense in State & Federal Public Policy: Individual and Family Support" Allan Bergman
5:00 - 5:20	Linda Steir, Leadership Graduate & Family Support Coordinator in Region 10
5:20 - 5:40	Your Pressing Issues
5:30 - 6:00	Appetizer Break
6:00 - 7:00	"A Trip Down Memory Lane" Allan Bergman
7:00 - 7:30	Small Groups on Your Pressing Issues
7:30	Dinner & Conversation

Agenda

SESSION V, DAY TWO:
Using the Legislative Process to Create Change

At the Legislative Office Building

7:30 - 9:00	Breakfast at the State House Cafeteria
9:00 - 10:30	Small Group Planning
0:30 - 12:00	Meetings with Legislators
12:00 - 1:30	Lunch at the State House Cafeteria
1:30 - 2:00	Debriefing with Allan Bergman
2:00 - 4:00	"News from The Hill: What's Real ... What's Not" Allan Bergman in Representatives Hall, Legislative Office Building

Coming Attractions

Community Organizing with ADAPT

Agenda

SESSION VI:
Community Organizing

12:00 - 1:00	Registration and LUNCH - Exeter Room
1:00 - 1:30	"Welcome" - Don Shumway, Director, Division of Mental Health and Development Services
1:30 - 2:15	Participant Updates
2:15 - 3:15	Introduction to Community Organizing
3:15 - 3:30	Break
3:30 - 4:00	Leadership Panel: Jim Piet Eileen McCall Glee Hooper
5:00 - 5:15	Appetizer Break
5:15 - 5:30	"We Are Speaking For Ourselves" Video
5:30 - 7:00	Community Organizing: Stephanie Thomas, ADAPT
7:00 on...	Dinner at the Ashworth - Rose Room

Agenda

SESSION VI, DAY TWO:
Community Organizing

7:30 - 8:30	Breakfast
9:00 - 11:00	Organizing Your Community
11:00 - 11:30	Break and Check Out
1:30 - 12:30	Nuts, Bolts, and Strategies
12:30 - 1:30	Lunch in the Rose Room
1:30 - 3:00	Action Planning
3:00 - 3:30	Debrief about original expectations
3:30 - 4:00	Closing Celebration and Plans for the Future

Appendix F

FIELDWORK ASSIGNMENTS

"I learned that all people should be treated right and have a fair shake out of life."

[redacted]

FIELDWORK ASSIGNMENT #1

What is your vision for yourself, your family, your future?

What is your nightmare?

Bring a photo of yourself and your family to the next session.

Be creative. You can write, type, make a photo collage, use a tape recorder to complete this assignment!

FIELDWORK ASSIGNMENT #2

1. If you still haven't done so, bring pictures of you, your family, and key people in your life to the next session.

2. Describe one change you would like to make to assist you in achieving your vision.

   What are five steps to achieving this change?

3. Answer the following questions one day and again two weeks after this session:

   What thoughts, ideas, or activities from the Leadership Series stand out for you?

   What made them meaningful for you?

   How might you use them in your own life?

   Do you think these ideas might make a difference for you?

   Why?

FIELDWORK ASSIGNMENT #3

- Read all of the handouts you received during this session.
- Define assistive technology.
- Come up with a list of all of the assistive technology resources available in New Hampshire.
- Bring in pictures of assistive technology that you find in everyday life.
- Check in with other members of your Leadership Group to find out how they're doing.
- Begin working on the steps to achieving your vision. Record your progress.

FIELDWORK ASSIGNMENT #4

- Find your legislator's name, address, and phone number in the book of legislators.

- Write and invite him/her to our next session. In the letter, give them your phone number and/or ours to call for more information.

- This letter should be sent out as soon as possible so they put you on their schedule of important things to do. (A sample letter is enclosed).

- Let us know who you invited and the responses so we can plan the next session accordingly.

- Attend a meeting. This could be anywhere — city council, planning board, school board, area agency meeting or facilitated communication support group at your area agency, etc.

SAMPLE LETTER

Dear Representative (personalize):

My name is Beth Dixon and I live on Dunklee Street in Concord, New Hampshire. I am the parent of four children who have grown up and attended school in Concord. My youngest son, Andrew, attends Rundlett Junior High School. He also experiences a variety of disabilities that require support for him to learn. As a result of my experiences with Andrew, I have gotten involved with the New Hampshire Leadership Training Series.

As a participant of the Leadership Series, I have been learning about best practices for people with disabilities. These practices include: attending local schools and regular classes; living and receiving support at home; being employed in real jobs; and, having access to the supports necessary to manage the overall needs of individuals and families to live, work, and play alongside family, coworkers, and friends in the community.

As one of the final session in this six-part Series, we will become familiar with the legislative process and learn about citizen involvement in public policy and government decision making. Mr. Allan Bergman, Director of Governmental Relations, United Cerebral Palsy Association, Washington, DC, will facilitate this event.
I would like to invite you, as a member of the (name the committee i.e. education committee) to join a discussion about the legislative process with other parents who have children with disabilities and individuals with disabilities. This session, sponsored by the UNH New Hampshire Leadership Series, is scheduled for (date, time) at the Legislative Office Building.

The session is informal, lasting two hours. No preparation is necessary on your part. Lunch will be served following the session. We hope you will be able to join us. Please call me to confirm your participation (telephone number) or the New Hampshire Leadership Series (telephone number) if you have any questions.

Sincerely,

(your name)

FIELDWORK ASSIGNMENT #5

- Write a thank you letter to the legislators who attended the session. Make sure you outline your issues in your letter.
- Research the organizations in New Hampshire responsible for community organizing and citizen advocacy.
- Interview the organizations that appeal to you to find out exactly what they do.
- Record your interview.

Appendix G

BUDGET AND FUND RAISING STRATEGIES

"With support and information, expectations can be increased and possibilities realized."

LEADERSHIP SERIES COSTS

Personnel		
Family Leadership Coordinator	.25% FTE	$ 5,500
Coordinator Benefits	33.5% of $5,500	$ 1,843
5 Facilitators	$100 per session x 6 session	$ 3,000
Contracted/Purchased Services		
2 Presenters	$600/session x 6 sessions	$ 7,200
Presenter travel	$800 x 12 presenters	$ 9,600
Respite	$40/day x 12 days x 35 participants	$16,800
Participant travel	$.28/mile x @ 100 miles x 35 participants x 6 sessions	$ 5,880
Overnight accommodations	6 nights x $65/room x 25 rooms	$ 9,750
Meals	45 participants x $20/pp x 12 days	$10,800
Rental Conference Sites	$150/day x 12 days	$ 1,800
Rental Equipment	$80/day x 12 days	$ 960
Postage		$ 500
Telephone		$ 1,500
Copy/Printing		$ 900
T-shirts	75 x $8/each	$ 600
TOTAL		$75,633

Dear (personalize):

This is to confirm our request to the DD Council for $10,000 to support this year's New Hampshire Leadership Series. As you are aware from your previous funding of New Hampshire Leadership, this Series has been an extremely effective training vehicle for self-advocates and families of children with disabilities. The Series will continue to assist parents and consumers to become more active and effective in the development of quality services and educational programs for their children and themselves.

This time we will bring together 30 family members and people with disabilities for twelve days of workshops during (dates). All materials, lodging, travel, childcare/respite, meals, and supports needed to attend will be covered for the participants. The cost have been historically underwritten collaboratively between the Institute on Disability and the DDC, with sponsorships from Family Support Councils and Area Agencies.

At any time during the Series, you or members of your staff are welcome to attend the sessions. Please contact me at 228-2084 if anyone from the DDC plans to attend. The dates will be available as soon as we have confirmed dates with several presenters.

Let me know if you require any further information. Thank you.

Sincerely,

Beth Dixon

[redacted]

Dear (personalize):

Once again, it's Leadership Series time in New Hampshire!

The Institute on Disability, UAP is sponsoring the seventh annual New Hampshire Leadership Series. This year's series is new and improved - we are now bringing together 30+ parents and individuals with disabilities for 12 days of intensive information sharing and leadership development.

In order to sustain this valuable opportunity, we are once again requesting financial support from a wide variety of organizations. In the past, financial support has come from Area Agencies, Family Support Councils, the Developmental Disabilities Council, Department of Education, and the Division for Mental Health and Developmental Services. This broad-based support has allowed this Series to educate a large number of leaders from all regions in our state. Because the Series has been expanded from 6 to 12 days, we are no requesting $1,000 per participant. For each $1,000 that you contribute, a parent or consumer can attend the series and receive full support (respite, travel, personal support, meals, lodging, workshop materials, etc.) to insure their uninterrupted participation in the event.

The overall goals of the New Hampshire Leadership Series remain the same. The Series is designed to bring together highly motivated parents and individuals with disabilities and provide them with state-of-the-art information and strategies to overcome many of their shared issues. Participants gain skill and knowledge that assist them to become active leaders in the development of better supports and services for individuals with disabilities in our state.

Leaders in the field of disability and community supports, along with New Hampshire parents and individuals with disabilities who have achieved positive change in their lives, will be active participants as presenters and group facilitators during each of the six, two-day workshops.

Participants will be selected based on: 1) their interest and ability to organize other family members, 2) geographical location; and 3) their commitment to attend all of the training sessions.

Applications to attend have been pouring in from all around the state and we are looking forward to an exciting training and learning opportunity!

Please complete the enclosed form and indicate how many parents and/or individuals with disabilities you will be able to sponsor. If you have any questions or would like further information, please feel free to call me at the Office for Training and Education Innovations in Concord at 228-2084. Thanks very much for your consideration.

Sincerely,

Beth Dixon,
Family Leadership Coordinator

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NEW HAMPSHIRE LEADERSHIP CONTRIBUTION/SPONSORSHIP FORM

Name _____
Address _____
_____
Telephone _____

_____ Yes, our organization is pleased to sponsor a participant(s) at the next New Hampshire Leadership Series. We have enclosed our check or letter of commitment.

_____ Yes, we would like to sponsor _____ participant(s). Please call for details.

_____ We are unable to sponsor a participant, but would like to provide other resources to the Family Leadership Series (e.g., paper, sponsor a dinner, t-shirt expenses, mailing costs, etc.). Please call for details.

_____ We are unable to make a financial commitment to the New Hampshire Leadership Series at this time.

Thank you for your support! We would appreciate a response by (date). The first session will begin (date) and we have applications from all regions. Please make your check payable to the University of New Hampshire and mail in the self-addressed envelope.

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Notes

Notes

About the Institute on Disability/UAP

The Institute on Disability at the University of New Hampshire was established to provide a coherent University-based focus for the improvement of knowledge, policy, and practice related to the economic and social participation of persons with disabilities in New Hampshire. The Institute, together with the Center for Genetics and Child Development at Dartmouth Medical School, The Institute for Health, Law, and Ethics at Franklin Pierce Law Center, and the Institute on Emotional Disabilities at Keene State College, comprise New Hampshire's University Affiliated Program (UAP) in developmental disabilities. The mission of the Institute is to promote the full inclusion of people with disabilities into their communities.

Institute on Disability
Office for
and Education
The Concord Center
Concord, NH
603-228-
603-228-
Institute.Disability.Com
http://iod.unh.edu

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